Cochrane Patient and Public Involvement Executive's Strategy Summary 2027–2032

Summary for public feedback – June 2026

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This summary has been prepared by the Cochrane Patient and Public Network Executive. This summary is informed by a global survey (258 responses from 62 countries, November–December 2025) and ongoing co-design activities. We are sharing it to gather your feedback through two public webinars, and via email, before the Strategy is finalised.

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Introduction

This Patient and Public Involvement Executive's (PPI) Strategy updates the five-year plan developed in 2022. That plan was developed through the combined efforts of the PPI Network Executive (then known as the Consumer Network Executive) and Cochrane staff and groups. The previous plan can attest to a number of successes and served as the infrastructure for the continued development of PPI at Cochrane over the past five years.

[We could insert one or two success stories in a dialogue box that tie back to previous plan goals?]

The past five years have realised profound changes in the dissemination of health research and health information for the general public, patients and healthcare professionals. They have also brought profound challenges in combatting the volume and sophistication of mis- and disinformation, which can cause dangerous confusion and undermine trust both in evidence itself, and in the people and organisations involved in developing it. This is one of the drivers for significant and transparent integration of patient and public involvement (PPI) across Cochrane: to contribute to rebuilding global trust through open and authentic collaboration with the people most impacted by the evidence. We have designed our draft Strategy to respond to these changes. In developing this update the PPI Network Executive has conducted a detailed survey, and reached out to Cochrane groups. We are now holding discussion sessions to provide an opportunity for feedback and to inform the direction of the PPI Strategy for Cochrane for the next five years. Our draft Strategy establishes a two-pronged approach to priorities: one to eighteen months, and eighteen months to five years. This will allow us to prioritise critical activities in the first eighteen months and then to evaluate priorities in the final years of this plan.

In our work on this update we have found that people want to contribute more to Cochrane and to have easier access to the critical evidence it produces. We also heard, clearly and consistently, that some patients and members of the public should be paid for their time, so that involvement is not limited to those who can afford to volunteer. Our goals are built around seeking improved methods and access to make this possible. Our plan and goal is for a more robust and inclusive PPI community which facilitates meaningful involvement that is critical to Cochrane's overall success.

Priority Short-Term Actions (0–18 months)

These actions address the most urgent, systemic barriers and can be initiated relatively quickly with focused resource allocation.

Priority Short-Term Actions
1. Make getting involved effortless Launch a clear, welcoming 'How Patients and the Public can Get Involved' hub on the Cochrane website, with a step-by-step guide, pathways by interest/experience level, and a direct point of contact for queries. For those who want to become involved, provide a 'Welcome and Orientation' to the PPI Network, member expectations and information on opportunities. Where possible, provide a single, clear entry point that reduces the need to navigate multiple Cochrane websites and logins — fragmented systems were one of the most frequently reported barriers.
2. Build a connected, responsive community: Introduce proactive, personalised opportunity matching by actively emailing PPI Network members about relevant tasks (rather than expecting them to log in and search), with a simple, fast response mechanism.
3. Remove the barriers that keep people out: Fund, design and establish a pilot project for compensation for identified PPI contributors, including developing a standardised reimbursement framework aligned with NIHR recommended rates, with flexible payment options and waivers for people in regions or circumstances where compensation may affect their benefits or entitlements. Use evaluation of the pilot project to expand the project to all Cochrane groups.
4. Make engaging with evidence easier: Redesign Plain Language Summaries using layered formats: a short headline finding, a patient-friendly visual summary (infographic, short video, audio or comic-book-style formats that appeal to younger audiences), with links to the full review for those who want more detail. Identify a set number of broadly applicable reviews and form a workgroup to develop patient-friendly formats in conjunction with those authors and the PPI Network. Once a PPI-friendly format is established, determine an implementation strategy.
5. Meet the moment: respond to the rise of AI: Respond to the growing use of Artificial Intelligence (AI) for health information. Patients and the public are increasingly turning to AI tools for health-related information and guidance. Working with patient and public partners, co-design and pilot and co-evaluate the use of AI tools to help people navigate trustworthy evidence about their health questions.

Priority Long-Term Initiatives (18 months–5 years)

These initiatives require sustained investment, partnerships, and structural change — but are essential to transforming Cochrane's PPI from episodic to embedded.

Priority Long-Term Initiatives
1. A truly global community: Develop a global, multilingual Patient and Public Network with active community features: regular newsletters, member expectations, peer learning circles and communities of practice, shared forums, and opportunities to meet other contributors, together with simple ways to recognise and celebrate members' contributions — moving from passive registration to genuine community membership.
2. Embed patient and public voices at every level: Work with the Cochrane Board to determine the best methods of having patient and public involvement and influence at every level of Cochrane governance, including key management groups, editorial boards, geographic and thematic groups, and strategic decision-making bodies, moving beyond review-level involvement.
3. Build a structured PPI training ecosystem: tiered modules for public contributors (evidence literacy, AI and health data literacy, review processes) and for Cochrane authors/groups — including training on managing power dynamics and making involvement meaningful — building on current research in this area and using success stories that demonstrate the value of patient and public involvement.
4. Secure long-term, sustainable funding: Develop a sustainable funding model to support PPI in evidence synthesis, exploring routes such as working across organisations to pool resources, creating dedicated grant streams, strengthening institutional partnerships and pursuing aligned funding mechanisms (for example research-funder schemes).
5. Create a global PPI Ambassador and Coordinator programme. Deploy local PPI coordinators within geographic/thematic groups to facilitate bridging the work of Cochrane's international network and local patient communities, including prioritising representation from Low- and Middle-Income Countries.
6. Expand partnerships to amplify reach and fight misinformation: Strengthen external partnerships to widen reach and access — for example collaborating with Wikipedia / the Wikimedia Foundation, health media, patient organisations and other trusted online channels — to make Cochrane evidence easier to find and to help counter health misinformation.

Values to Guide this Strategy

Survey respondents identified a set of core values that should guide the future development of Cochrane's Patient and Public Network — and which could also guide the wider work of Cochrane. Ranked by how often they were mentioned, the values most frequently identified were:

Inclusion and representation (23.3%) — actively seeking diverse voices by geography, condition, background, language and experience, so involvement reflects the communities affected by health evidence.

Transparency and openness (21.8%) — clear processes, open decision-making, and showing people how their contributions influence outcomes.

Accessibility, clarity and usability (16.3%) — information and opportunities that are easy to find, understand, navigate and use.

Equity and fairness (14.9%) — reducing structural barriers to involvement, fairly recognising contributions, and addressing global imbalances in who is able to take part.

Impact and relevance (14.4%) — ensuring involvement adds real, demonstrable value to reviews, to people's lives, and to health outcomes.

Collaboration and partnership (13.4%) — working with patients and the public as genuine partners, moving from consultation to co-production.

Please note: The survey identified ten values in total; the full ranked list — which also includes respect and dignity; communication and engagement; ethics and integrity; and trust and trustworthiness — is available in the survey analysis. Respondents also raised free or open access to the Cochrane Library and stronger external partnerships (such as Wikipedia); we will note these even where they sit beyond the PPI Network's direct remit.

Together, these values emphasise that meaningful patient and public involvement requires not only opportunities to be involved, but organisational structures that support equity, respect and shared decision-making.

Key Topics for Discussion

There will be an opportunity to provide feedback at the webinars, or alternatively you can contact msalman@cochrane.org

We would particularly welcome your views on three questions arising from the survey and this draft:

- **When to pay people for involvement.** The survey's clearest message was that unpaid involvement excludes people who cannot afford to volunteer. What would fair, flexible compensation look like across different countries and circumstances — and how should paid and volunteer roles work alongside each other?
- **AI and trustworthy health evidence.** People increasingly turn to AI for health information, while mis- and disinformation undermine trust. Should Cochrane co-design AI tools with patients and the public — and what role should patients and the public play in shaping how Cochrane uses AI?
- **From joining to belonging.** Many people register to get involved but then feel disconnected. What would help you find your way in — clear pathways, proactive matching to opportunities, orientation, community features — and what would keep you involved?

If time allows, we would also like to discuss: patient and public voice at every level of Cochrane governance; and making Cochrane evidence easier to find, understand and use (formats, languages and channels).